

PANDAS and PANS

What School Counselors Need to Know to Identify Possible Patients

For Counselors Only Conference

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POLL:

Question 1: How many of you have heard of the diagnoses PANDAS or PANS?

Question 2: Have you identified or worked with a PANDAS or PANS patient?

PANDAS and PANS Acronyms

PANDAS:

Pediatric
Autoimmune
Neuropsychiatric
Disorder
Associated with
Streptococcus

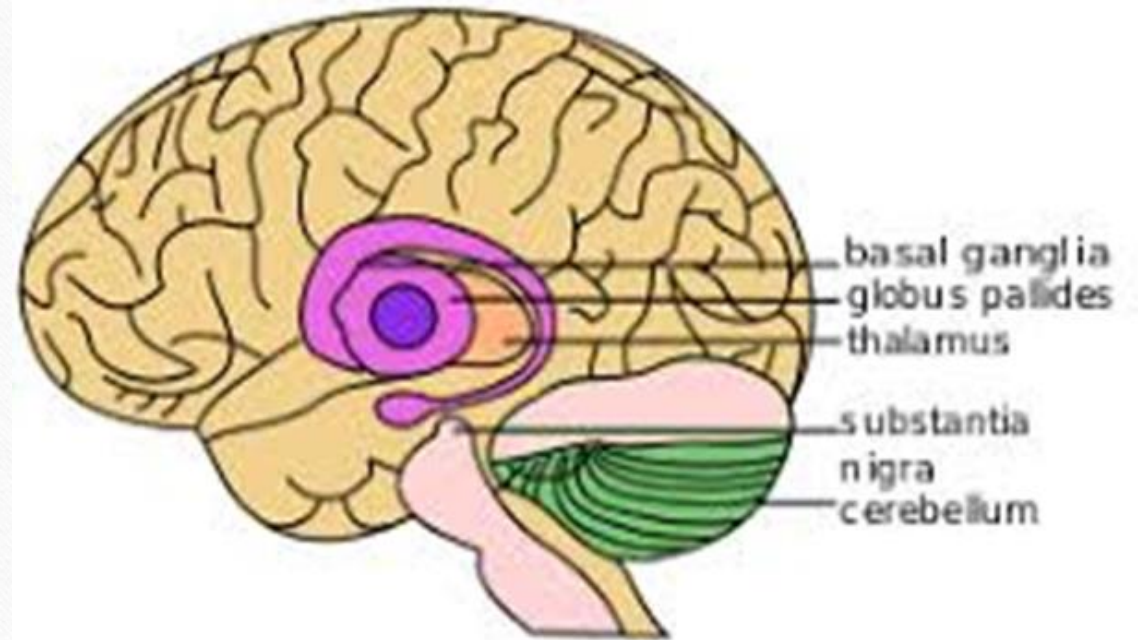
PANS:

Pediatric
Acute onset
Neuropsychiatric
Syndrome

But what are these disorders really?

PANDAS and PANS
are acronyms and
common terms for
Basal Ganglia
Encephalitis or BGE

Basal Ganglia and Related
Structures of the Brain



What does the Basal Ganglia control?

- Emotions
- Mood
- Movement
- Balance
- Cognition
- Executive function
- Memory
- Procedural learning
- Habit formation

Most Common Causes of PANDAS/PANS

PANDAS

Always caused by
Group A Strep

PANS

Bacterial, viral and fungal infections
Mycoplasma (walking pneumonia)
Influenza
Herpes viruses
Tick borne infection (Lyme disease)
Candida (Yeast infections)
Staph infection

PANDAS Diagnostic Criteria

1. Presence of OCD and/or tics, (vocal and motor)
2. Age requirement (onset between age 3 and puberty)
3. Acute onset with relapsing and remitting course
4. Association with Group A strep infection
5. Association with neurological abnormalities

PANS Diagnostic Criteria

1. An abrupt, acute, dramatic onset of obsessive-compulsive disorder or severely restricted food intake
2. Concurrent presence of additional symptoms with similarly severe and acute onset from at least 2 of the following categories:
 - Anxiety
 - Emotional Lability and/or Depression
 - Irritability, Aggressive or Severe Oppositional Behaviors
 - Behavioral (Developmental) Regression
 - Sudden Deterioration in School Performance
 - Motor or Sensory Abnormalities
 - Somatic Symptoms, including Sleep Disturbances, Bedwetting
3. Symptoms not better explained by a known medical disorder
4. Age requirement – None

PANS/PANDAS

Know the Signs. Know the Treatments.

Behavioral Regression

You can see the difference between the self-portrait during a PANS flare with regression and the self-portrait while the child was healing.

During Flare



In Treatment

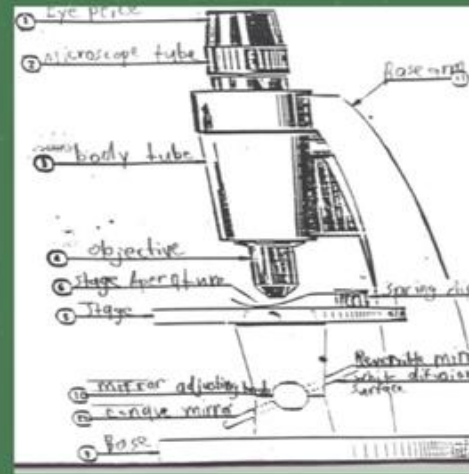


If a Child has Sudden, Acute Onset of OCD and/or Food Restriction & Multiple Neuropsychiatric Symptoms, Consider PANS/PANDAS.

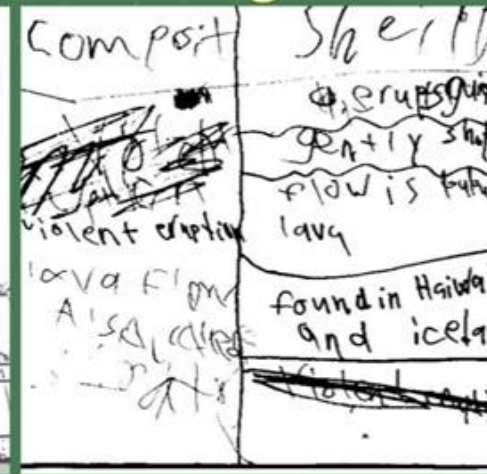
Handwriting Deterioration

Prior to acute onset of PANDAS, the student could write neatly. After, handwriting becomes almost illegible and not neatly placed on the paper.

Before PANS



During Flare



Images Credit: Susan E. Swedo, M.D. Pediatrics & Developmental Neuroscience Branch NIMH, NIH Intramural Program

PANDAS and PANS are OFTEN MISDIAGNOSED

Most common misdiagnoses:

- Obsessive - compulsive disorder
- Anxiety disorder
- Attention deficit hyperactivity disorder
- Tourette syndrome
- Asperger's syndrome or other autism spectrum disorder
- Oppositional defiant disorder
- Pervasive developmental disorder
- Conversion disorder

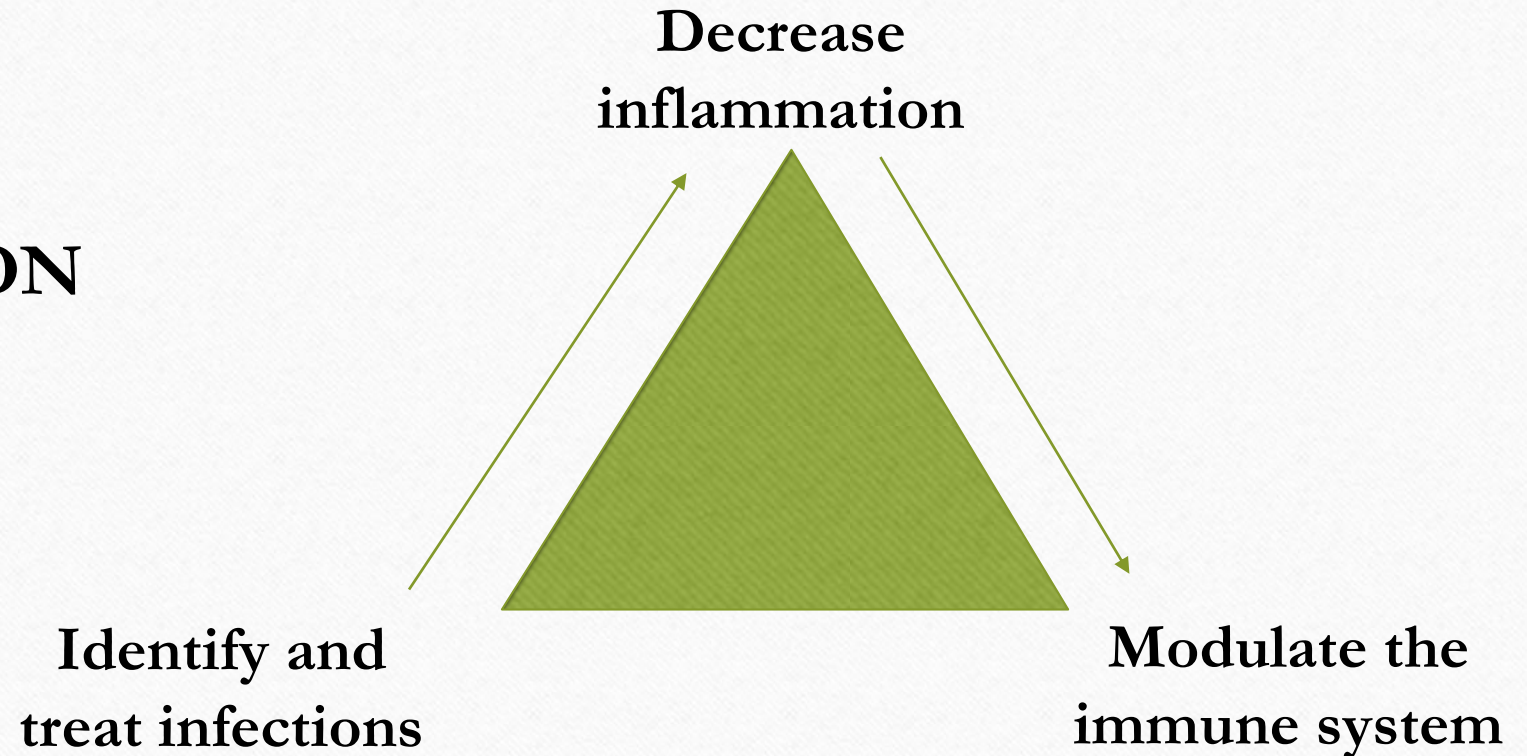
Challenges Faced By Patients and Parents

Finding a provider who:

- recognizes PANDAS and PANS
- is located within a reasonable geographic distance
- will see patient early, preventing the disorder from becoming chronic
- accepts medical insurance
- will advocate for insurance coverage for immune modulating therapy

The 3 I's Approach to Treatment

- **INFECTIONS**
- **INFLAMMATION**
- **IMMUNITY**



Why should School Counselors be aware of PANDAS and PANS?

The Ultimate price of missed or misdiagnosis




Max Wallace, 13 years old, died by suicide on Christmas Eve 2016, just one week before he was to receive immune modulating treatment.

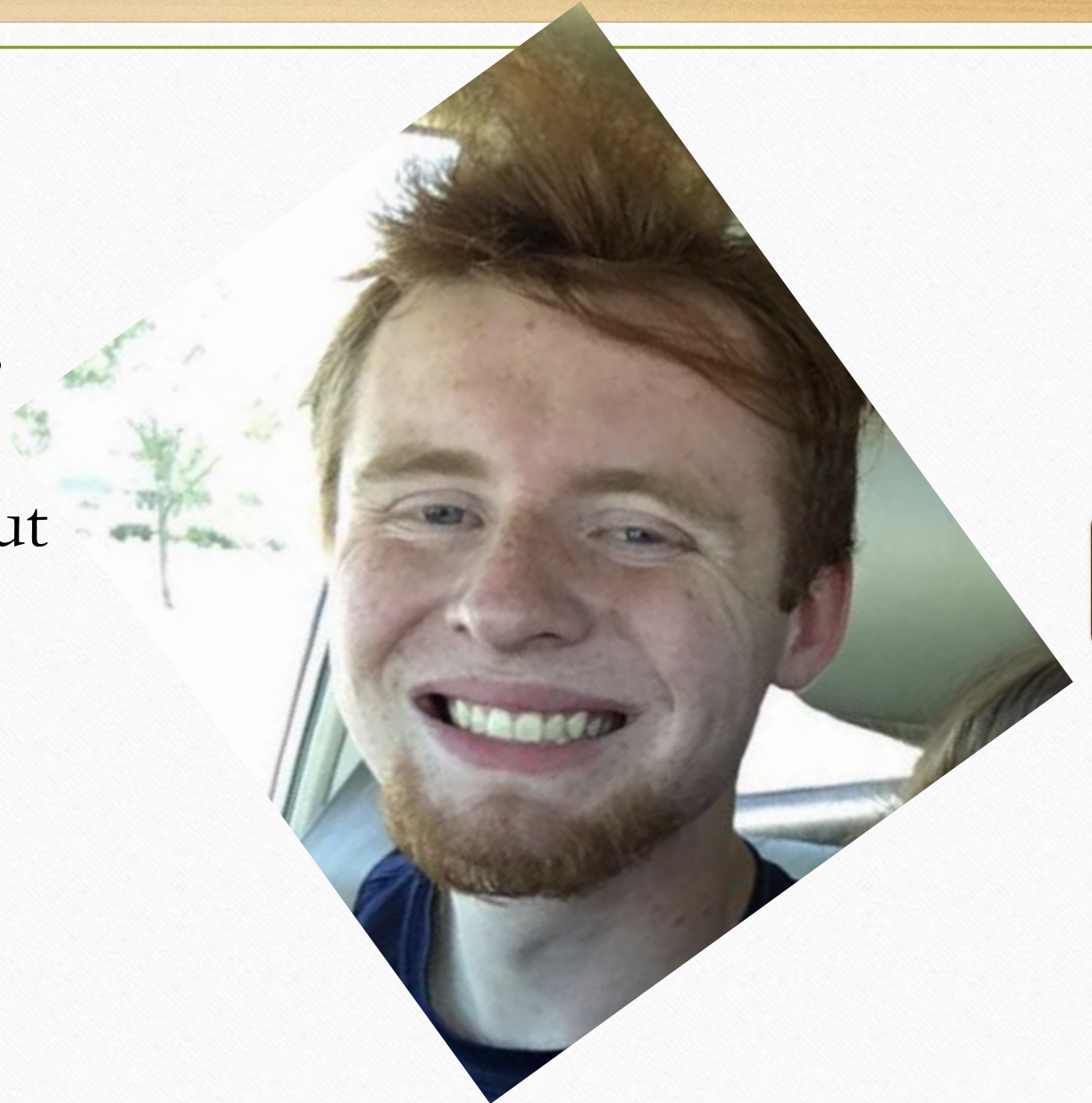
"I want everyone to know we lack providers," says Max's mom, a health care provider. "We lack awareness, and we lack cooperation from our pediatricians. I want families to know we can no longer take 'no' for an answer from our doctors."



Alex Manfull, 26-year-old Princeton graduate, died by suicide in 2018 just 2 weeks before she was to receive immune modulating treatment.

18-Year-Old Isaac McMillin
died by suicide September 23,
2019. His friends knew
something was very wrong, but
no one said anything to his
parents.

 He Who
Laughs |
Championing
Mental Wellness



POLL:

Looking back, how many of you have think you may have seen or worked with a student who may have had PANDAS or PANS?

TAKEAWAYS FOR YOUR PRACTICE

- When a previously typical child presents with a new onset of neurologic or psychiatric symptoms, encourage consideration of an infection triggered autoimmune condition.
- Be prepared for pushback by providing relevant/timely professional data or articles.
- Ask the parents if there is a family history of autoimmune disease.
- Determine if the child had an infection or exposure in the previous weeks or months.
- Advocate for the child who may need accommodations in the classroom.
- Share information with colleagues.
- Support colleagues who identify a child and are met with negativity.

Resources



PANDAS Network -reliable information, a provider directory, and legislative information about state efforts toward insurance coverage for diagnosis and treatment

www.pandasnetwork.org

PANDAS Physicians Network – clinically focused, diagnostic flowchart, evidence-based treatment guidelines, articles and resources www.pandasppn.org

In a Pickle Over PANDAS (for patients) Melanie Weiss, RN, multiple languages

PANS, CANS, and Automobiles: A Comprehensive Guide for Helping Students with PANDAS and PANS
Dr. Jamie Candelaria Greene

PANDAS and PANS in the School Setting Patricia Rice Doran

My Kid is NOT Crazy https://www.youtube.com/results?search_query=my+kid+is+not+crazy

Stolen Childhood <https://www.youtube.com/watch?v=Cprp-zhkDCM>

Brain on Fire Book (Amazon) and Movie (Available on Netflix)

Peer-reviewed Journal References

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Thank you for your time and attention!

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<https://youtu.be/yIQEMcHoXlM>



<https://www.youtube.com/watch?v=3VnHiCB8yFU>